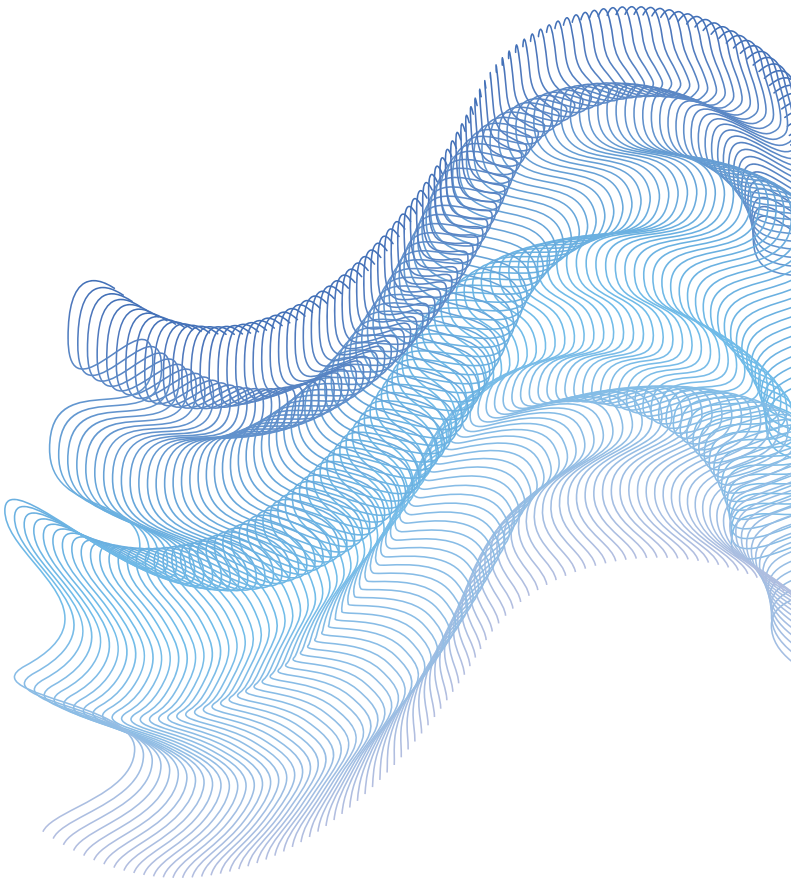
Chapter 1

General introduction



Introduction

Over the past few years, the importance of physical activity has increasingly been stressed for people with intellectual disabilities (ID). People with ID amount to approximately 1% of the general population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). An intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities, the International Classification of Diseases 11, and the Diagnostic and Statistical Manual of Mental Disorders as significantly sub-average intellectual functioning (an IQ standard score of approximately 70 to 75 points or below) and substantial limitations in adaptive behavior, which are both manifested before the age of 18 years. An intellectual disability can be divided into four levels of severity (mild, moderate, severe, and profound), where the distinction between severe or profound ID can be difficult to ascertain due to additional disabilities. Moreover, a high prevalence of mobility, sensory, and health problems among people with ID is a known fact (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Van Splunder, Stilma, Bernsen, Arentz, & Evenhuis, 2003; Van Timmeren et al., 2017), and one that has been established as definitively related to the level of severity of the intellectual disability. A specific subpopulation of people with ID are referred to as people with profound intellectual and multiple disabilities (PIMD) (Nakken & Vlaskamp, 2007). In these people, due to generalized brain damage, profound ID and severe or profound motor disabilities are prevalent and are usually accompanied by various sensory impairments (i.e., visual, auditory, taste, and smell problems) as well as general health problems (e.g., epilepsy, obstipation, a low level of alertness, sleeping problems, and challenging behavior). People with PIMD constitute a highly vulnerable group and are heavily dependent on others for all aspects of daily life (American Psychiatric Association, 2013; Nakken & Vlaskamp, 2007).

The positive effects of physical activity for people with ID have been summarized in a systematic review (Bartlo & Klein, 2011). Being physically active on a regular basis was shown to result in a multitude of benefits; evidence was found that physical activity positively influenced balance, muscle strength, and quality of life in people with ID (Bartlo & Klein, 2011). Recent studies have noted physical activity as evidence for improvements in cardiovascular fitness, mobility, self-efficacy (Hakim, Ross, Runco, & Kane, 2017; Oviedo, Guerra-Balic, & Baynard, 2014; Pérez-Cruzado & Cuesta-Vargas, 2016), and a decrease in anxiety states, body weight, and body mass index in people with mild to moderate ID (Carraro & Gobbi, 2012; Oviedo et al., 2014). A systematic review focusing on challenging behavior in people with mild to profound ID demonstrated that any intervention in which a form of leisure-based physical activity is undertaken can be an effective intervention in order to reduce existing challenging behavior (Ogg-Groenendaal, Hermans, & Claessens, 2014). However, in general, these studies were mainly focused on people with mild to moderate ID. That movement-oriented activities can also have significant value for people with severe to profound ID has been confirmed by a systematic review conducted by Houwen, Van der Putten, and Vlaskamp (2014). They reviewed the evidence related to movement interventions designed to improve motor, cognitive, or social outcomes in people with severe to profound ID, and predominantly found beneficial effects for the motor domain. Obtaining or maintaining (gross) motor skills is a precondition for the more independent performance of bodily movements produced by skeletal muscles, which results in energy expenditure (i.e., physical activity). Even more importantly, it is known that training and improvements in the motor domain promote cognitive, social, and emotional development (Diamond, 2000), which has also been observed in a few studies including children and adults with profound ID (Houwen, Visser, Van der Putten, & Vlaskamp, 2016; Lancioni et al., 2004; Van der Putten, Vlaskamp, Reynders, & Nakken, 2005; Whinnery & Whinnery, 2011).

By the same token, several studies have demonstrated that people with ID are in fact at higher risk of being physically inactive compared to the general population (Dairo, Collett, Dawes, & Oskrochi, 2016; Stancliffe & Anderson, 2017). A systematic review, including 15 studies that quantitatively measured levels of physical activity, has demonstrated that

a limited percentage of participants with ID in the studies (9%) achieved (an equivalent of) the global physical activity guidelines of 150 minutes of moderate-to-vigorous physical activity per week (Dairo et al., 2016). These studies most likely focused on the broad group of people with ID, and so they tend to be biased towards people with mild to moderate ID without additional physical or motor disabilities (Dairo et al., 2016). Although a relationship with the level of severity of the intellectual disability was found, only a very small number of the participants were reported as having severe or profound ID (Dairo et al., 2016). A large-scale study by Stancliffe and Anderson (2017) is consistent with similar findings that present strikingly low levels of physical activity among adults with ID, related to the severity of the intellectual disability (i.e., the more severe the levels of ID, the higher the risk of being physically inactive). Moreover, to a certain extent, the study of Stanclife and Anderson overcame a significant shortcoming found in the studies reviewed by Dairo and colleagues (2016) by including a substantial representation of participants with severe to profound ID (28%) and a small percentage of participants with severe motor disabilities (8.5%) (Stancliffe & Anderson, 2017). The strongest risk factor for physical inactivity in people with ID appears to be an additional motor disability, e.g., being non-ambulatory (Stancliffe & Anderson, 2017).

Physical activity has been an important topic of research into people with ID. The studies conducted, however, have mainly focused on quantifying levels of physical activity, the relationship with personal and environmental factors, or associations between physical activity and a variety of outcomes (Bartlo & Klein, 2011; Dairo et al., 2016; Pitchford, Dixon-Ibarra, & Hauck, 2018). Furthermore, despite the fact that they are likely to be at the highest risk of being physically inactive, little is known about this topic when it comes to people with PIMD. So far, in most studies, researchers have excluded people with PIMD, because data collection methods, measurements, and physical activity standards for the population without ID are those generally used (Hilgenkamp, Reis, Van Wijck, & Evenhuis, 2012; Robertson et al., 2000). However, as mentioned earlier, there is sufficient evidence that people with PIMD can benefit from motor training and activation interventions (Diamond, 2000; Houwen et al., 2014; Van der Putten, Vlaskamp, Reynders, & Nakken 2005). Moreover, given the severe problems existent in nearly all domains of human functioning among people with PIMD, and the benefits that motor training and activation can offer to them, research studies that include people with PIMD are badly needed. Furthermore, direct support professionals play a key role in the support provided to people with ID/PIMD. Only when we have an adequate understanding of their role, as related to perceived barriers, can direct support professionals be expected to perform and maintain interventions focusing on physical or motor activation for people with ID/PIMD. Moreover, addressing at-risk subgroups could be especially informative in regard to physical activity research in people with ID, and could be of great value to the larger goal of empowering physical activity in all people with ID.

Objectives and outline of the thesis

The central aim of this thesis is to broaden the knowledge about the motor activation of people with (profound) intellectual (and multiple) disabilities, and, if possible, to empower support related to them. Based on this central aim, the thesis is organized in the following chapters. Each chapter presents a single study and was written so that it could be read independently from the rest. Therefore, the terms "motor activation" and "physical activity" will be used interchangeably in this thesis; we will reflect later on this in the general discussion.

Chapter 2 addresses the results of a study into the motor activation of people with PIMD in daily practice, and analyses how this relates to personal and environmental factors.

Chapter 3 presents a comprehensive review that qualitatively synthesizes previous research on barriers to and facilitators of physical activity in people with ID from three perspectives (factors, level of ID, and stakeholders).

Chapter 4 summarizes the results of an exploratory study into factors that influence direct support professionals and proposes a conceptual model for understanding the behavior of

direct support professionals in terms of physical-activity support for people with ID.

Chapter 5 introduces the psychometric properties of a newly developed tool to investigate direct support professional behavior when supporting people with ID in their physical activity.

Chapter 6 addresses results about how characteristics of people with ID and characteristics of direct support professionals are related to professionals' behavior regarding their support in promoting physical activity in people with ID.

Chapter 7 presents an evaluation of an intervention that has potential for promoting motor activation among people with PIMD in terms of its feasibility and potential effects.

Chapter 8 provides a general discussion, in which the findings of the preceding chapters are related to the central aim of the thesis. This final chapter also includes a theoretical and methodological reflection, and discusses directions for future research and policy.